

Deciding about fertility preservation after specialist counselling

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Submitted on January 24, 2014; resubmitted on May 8, 2014; accepted on May 14, 2014

STUDY QUESTION: How do female patients experience fertility preservation (FP) consultation (FPC) with a specialist in reproductive medicine and subsequent decision-making on FP?

SUMMARY ANSWER: Most patients had positive experiences with FPC, but negative experiences were found to be associated with decisional conflict and decision regret.

WHAT IS KNOWN ALREADY: When confronted with a need for gonadotoxic treatment, girls and young women will have to make an irreversible decision with regard to FP. Patients may experience decisional conflict and develop regret about their decision during follow-up. Patients' opportunities to ask questions during FPC and their knowledge about FP have been inversely related to decisional conflict.

STUDY DESIGN, SIZE, DURATION: A questionnaire on experiences with FPC, designed after qualitative research, was retrospectively distributed to 108 patients to whom FP was offered after FPC between July 2008 and July 2013. Aiming to minimize recall bias, we defined a subgroup of patients counselled since 2011 who had not yet tried to conceive after FPC.

PARTICIPANTS/MATERIALS, SETTING, METHODS: Patients were aged ≥ 16 years and had either cancer or a benign disease that required gonadotoxic therapy. They received FPC in a single university hospital in the Netherlands. Apart from patients' experiences, patients' characteristics, decisional conflict and decision regret were assessed.

MAIN RESULTS AND ROLE OF CHANCE: A total of 64 patients (59.3%) responded to the questionnaire. Patients generally had positive experiences with FPC, but indicated room for improvement. Negative experiences were associated with decisional conflict regarding the FP decision (not enough time for counselling: $P < 0.0001$; not having the opportunity to ask all questions during FPC: $P < 0.0001$; not feeling supported by the counsellor during decision-making: $P = 0.0003$; not all applicable options were discussed: $P = 0.0001$; benefits and disadvantages of FP options were not clearly explained: $P = 0.0005$). Decisional conflict was correlated to decision regret ($P < 0.0001$). In the subgroup of patients counselled after 2011 who had not tried to conceive ($n = 33$), similar results as for the total study population were found for the association of patient experiences with decisional conflict.

LIMITATIONS, REASONS FOR CAUTION: Given our retrospective design, we were not informed about the causality of the associations observed. We studied Dutch patients who were counselled in a single centre and were at least 16 years old when filling in the questionnaire. This may limit the generalizability of our data to other settings and populations.

WIDER IMPLICATIONS OF THE FINDINGS: More attention should be paid to improving FPC care. Interventions aiming at improving patients' comprehension of the topic of FP and their feelings of being supported in decision-making are advisable.

STUDY FUNDING/COMPETING INTEREST(S): This work was supported by the Radboud Institute for Health and an unconditional grant from Merck Serono. The authors have declared no conflicts of interest with respect to this work.

Key words: patients' experiences / fertility preservation / decisional conflict / regret / cancer

Introduction

Saving the potential to have biological children after cancer seems to be of high importance to many girls and young women with cancer (Tschudin and Bitzer, 2009). Cancer therapy may have gonadotoxic side effects and thereby threaten fertility (Larsen et al., 2003; Morgan et al., 2012). Various fertility preservation (FP) techniques have evolved with the aim of safeguarding the childbearing capacity of patients with cancer or benign diseases requiring gonadotoxic treatment (Friedler et al., 2012; Donnez et al., 2013; Garcia-Velasco et al., 2013). As FP techniques should ideally be performed before the start of gonadotoxic treatment, decision-making on FP needs to take place within a very short time frame.

To enable patients to make a well-informed decision on FP in the burdensome time period after cancer diagnosis, clinical guidelines advise FP consultation (FPC) with a counsellor specialized in reproductive medicine (Loren et al., 2013; Joshi et al., 2014; COSA). With respect to FPC care, it has been found that patients who have had opportunities to ask questions and who had extensive knowledge about FP had less decisional conflict (difficulties in decision-making) than those who had less knowledge or who felt less opportunities to ask questions (Peate et al., 2011, 2012; Kim et al., 2013). Decisional conflict is defined as a state of uncertainty about a course of action (O'Connor, 2010) and may very well be a forerunner of regretting the FP decision made (Peate et al., 2012).

In American studies where not all citizens have the costs of FP techniques reimbursed, 28.8% of the patients indicated FP treatment to be cost prohibitive (Mersereau et al., 2013), whereas 48% reported that costs influenced their FP decision (Hill et al., 2012). Patients who reported that the costs of FP influenced decision-making had a median decisional conflict score of 37.5 on a scale of 0–100, whereas others scored 21.9 (Kim et al., 2013). In a second study, patients for whom FP services were cost prohibitive had a mean decisional conflict score of 56.3, compared with 32.8 for patients who indicated that FP services were not cost prohibitive (Mersereau et al., 2013). Due to the health insurance system in the Netherlands where we conducted our study, patients do not have to pay for FPC and FP techniques. For this reason, we could exclude decisional conflict based on financial concerns and investigate the actual association between FPC experiences and decisional conflict. In the current study, we aimed to investigate how female patients experienced FPC and FP decision-making. As a second aim, we investigated the interplay between patients' FPC experiences, decisional conflict and decision regret. With the results of the current study conducted in a setting with reimbursement, we aimed to gain insight in the importance of FPC care and to contribute to developing interventions that might help patients to make high-quality FP decisions.

Materials and Methods

Study design

We performed a single centre, cross-sectional study querying women after FPC, via a questionnaire which was partly developed specifically for this study and partly consisted of validated scales. The questionnaire was distributed by mail to patients who received FPC between July 2008 and July 2013. Data from the questionnaire were complemented with data from the medical files.

Eligibility criteria and setting

Our study was conducted at the department of reproductive medicine of a single academic hospital in the Netherlands, the Radboud University Medical Center (Rumc). Patients were counselled about FP by one of the counsellors (seven gynaecologists and one nurse practitioner), of whom two gynaecologists actively participated in the Netherlands Network for Fertility preservation (NNF). Available FP techniques were ovarian transposition, the cryopreservation of embryos, cryopreservation of ovarian tissue (since 2009) and vitrification of oocytes (since 2011). Patients had the option to be referred to other centres for techniques that were not yet available at the Rumc. Information leaflets from the NNF about FP techniques were developed during the study period and provided if relevant. For the current study, women to whom FP was offered after FPC between 1 July 2008 and 1 July 2013 were considered eligible. For reasons of ethical approval, participants had to be at least 16 years of age at the time we conducted our study (November 2013). Women who were deceased ($n = 9$), severely diseased as a result of their diagnosis ($n = 5$), or who had severe psychological problems ($n = 1$), were excluded (Fig. 1).

Ethical approval

The Rumc's institutional ethics committee approved all of the study methods for patients who were at least 16 years of age at the time we conducted our study.

Questionnaire development

As we wished to interview a subset of patients that would best reflect our study population, women were recruited for the interviews via either the Rumc's 'Adolescent and Young Adult Cancer Taskforce' or via their gynaecologist (C.C.M.B.). All women who visited their gynaecologist during follow-up were consecutively invited to participate in semi-structured, individual interviews (45–75 min) with a single interviewer (L.B.). Of six patients contacted in total, one refused to participate. The patients interviewed had various oncological diagnoses, ages and partner-relationship situations at the time of FPC. Patients made a variety of FP decisions and differed from each other with respect to their medical and reproductive outcome. Patients were asked how they experienced FPC and FP decision-making and how they would reflect on their decision. As soon as saturation was achieved and no new themes came up after five interviews, no new interviews were performed. All interviews were recorded digitally, transcribed verbatim and coded by two medical researchers (L.B. and S.A.E.P.) independently following the concepts of grounded theory methodology (Charmaz, 2006). Disagreement was solved by consensus and a crosscheck by a qualitative research expert (W.L.D.M.). Based on the interviews, we developed the questionnaire items regarding baseline characteristics and patients' experiences with FPC.

Questionnaire outcome measures

Baseline and clinical characteristics

Based on the interviews, a total of 19 open and multiple-choice items relating to the patient's current situation and situation at FPC were included in the questionnaire. Items covered partner relationship, parental status, strength of the wish to have a child, educational level, current health status, patients' reproductive outcome and the use of assisted reproduction with or without cryopreserved material.

Experiences with FPC

Ten Likert scale items (five points) covered the relevant aspects of patients' experiences with FPC (strongly disagree–strongly agree), as indicated by our interviewees. The exact formulations of the individual Likert scale items in the questionnaire are provided in Fig. 2 and Table II. High scores on the

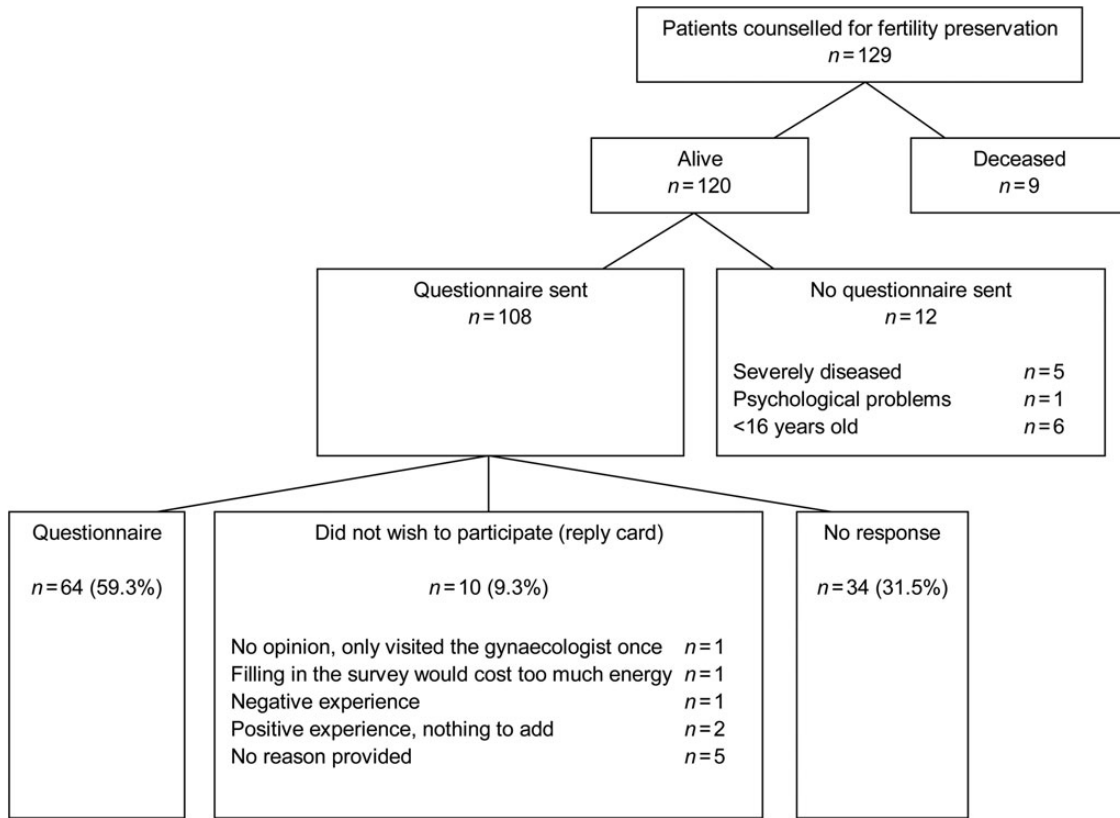


Figure 1 Flowchart: eligibility and response.

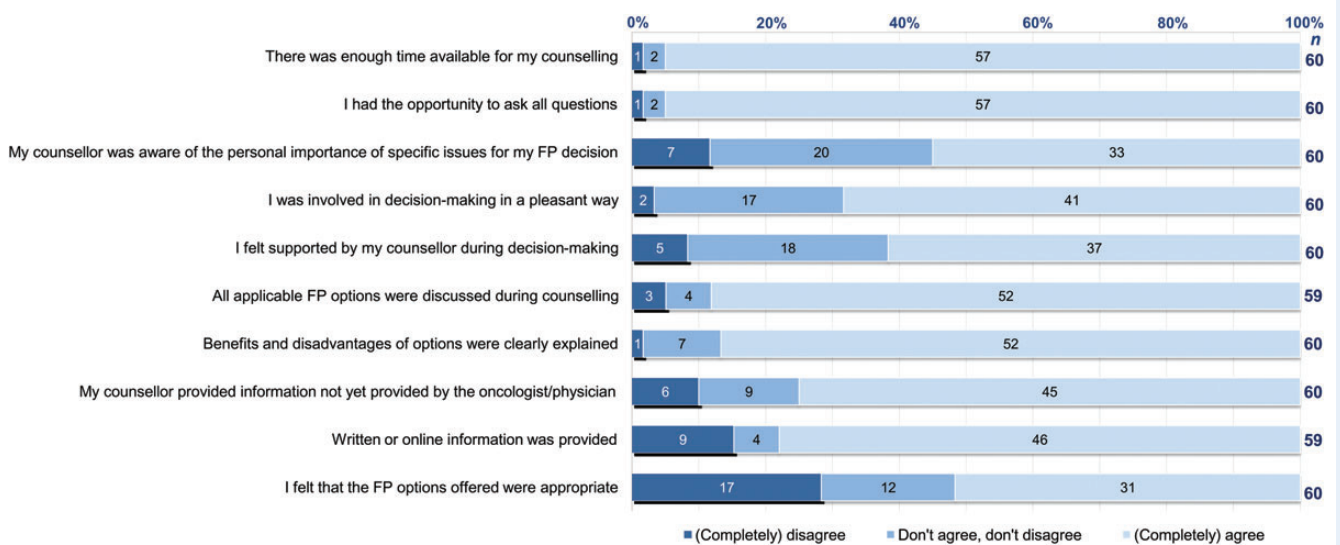


Figure 2 Patients' experiences with fertility preservation consultation (FPC). Percentages of patients (completely) disagreeing; not agreeing and not disagreeing or (completely) agreeing with 10 Likert scale items assessing experiences with the communication and patient involvement during FPC as well as the content of FPC.

items reflected positive experiences. In addition to the Likert scales, the questionnaire contained a free-response section in which patients could provide additional comments about their counselling experiences if they wished.

Decisional conflict

Patients ease or difficulty with FP decision-making was measured using a Dutch translation of the validated Decisional Conflict Scale (DCS) (Koedoot et al., 2001). This scale includes 16 items measuring 'a state of uncertainty about a course of action' during medical decision-making (strongly agree–strongly disagree) (O'Connor, 2010). We asked patients to reflect on the time period in which they decided on FP when filling in the questions. Given the retrospective design of our study, item 15 ('I expect to stick with my decision') was removed. Decisional conflict was thought to be greater when a person felt uninformed, was unclear about personal values, or felt unsupported at the time of decision-making. For this reason, the DCS contains the following subscales: 'Informed', 'Values clarity', 'Support', 'Uncertainty' and 'Effective decision' (O'Connor, 2010). As an example, one of the items was: 'I had enough advice to make a choice'. Items for decisional conflict were converted to a final score of 0–100 with higher scores representing higher decisional conflict. Scores below 25 are associated with an absence of decisional conflict, whereas scores exceeding 37.5 are associated with decision delay and feeling unsure (O'Connor, 2010).

Decision regret

A patient's current regret regarding her past FP decision was assessed using the validated Decision Regret Scale (DRS; five items), a five-point Likert scale measuring distress or remorse after a health-care decision (O'Connor, 2003). As an example, one of the items was: 'The choice did me a lot of harm'. As no validated Dutch version was available, the scale was translated to Dutch by one of the authors (L.B.) and back to English by an English native speaker. Only subtle translation flaws were identified and after three back-translation cycles, the Dutch and English versions were considered accordant. Sum-scores ranged from 5 to 25, with higher scores representing greater regret (O'Connor, 2003).

Data collection

To ensure that we would not distribute our questionnaire to deceased or severely diseased patients, broad information about patients' current health status was obtained from their FP counsellors or general practitioners. Subsequently, eligible patients (Fig. 1) received a paper version of the questionnaire by mail, together with a reply card on which they could indicate that they did not wish to participate. Patients received this questionnaire in either March 2013 (FPC before October 2012) or November 2013 (FPC between October 2012 and July 2013 and patients counselled before October 2012 who reached the age of 16 years between March and November 2013). If we did not receive a completed questionnaire or reply card after 3 weeks, one reminder was sent. Data retrieved from the questionnaire were supplemented with baseline and clinical information from medical files as well as information on the counsellor's experience with FPC and participation in the NNF.

Data analysis

Data analysis was performed using IBM SPSS Statistics version 20 for Windows (IBM corporation, Armonk, NY, USA). Differences with a two-sided P -value of ≤ 0.05 were considered to be statistically significant. Characteristics of responders and non-responders were compared using independent samples Student t -tests and χ^2 tests. The internal consistency of the questionnaire's items on FPC experiences was assessed by measuring Cronbach's alpha ($\alpha > 0.70$: reliable). Using ANCOVA, the influence of FPC experiences and other determinants on the overall decisional conflict

score (1) and the relation of this DCS score with decision regret (2) were assessed. As we performed multiple tests when assessing the influence of various variables on decisional conflict, a Bonferroni correction was performed. In addition to the ANCOVA, we obtained a Spearman correlation coefficient for the association between the DCS and DRS.

Apart from our total study population, we defined a subgroup of patients for whom we repeated the above-mentioned ANCOVA analyses and Spearman correlations for the following reasons. We could not exclude patients' recall bias with respect to their FPC experiences based on their knowledge about their (favourable or unfavourable) medical and reproductive outcome and current feelings of regret (Gilovich and Medvec, 1995; Hertwig et al., 2003). Patients who have decision regret may have cognitive dissonance (discomfort resulting from a bad decision) and try to cope with this dissonance by changing their opinion or reflection about the decision (Gilovich and Medvec, 1995). To minimize this bias, we defined a subgroup of women who were counselled since 2011 and who did not try to conceive after FPC. This subgroup also represents patients counselled in the time period in which all FP techniques were available at the Rmuc.

Results

Response

Out of the 108 patients who received our questionnaire, 64 patients (59.3%) participated (Fig. 1). Patients who did not fill in the questionnaire ($n = 44$) had similar baseline and clinical characteristics, follow-up characteristics and counsellor's characteristics as responders.

Participants

Out of the 64 patients who returned the questionnaire, 60 patients completely filled in the DCS. The characteristics of these 60 responders are provided in Table 1. A total of 33 responders to whom FP was offered had received FPC in the time since 2011 and had not tried to conceive.

Patients' experiences with FPC

The 10 items of our questionnaire measuring patients' experiences with FPC were reliable for our sample (Cronbach's $\alpha = 0.79$). In general, patients had positive experiences with FPC (Fig. 2). Despite this, a significant proportion of the respondents saw opportunities to improve: patient involvement and support, the counsellor's awareness of patients' personal importance of specific issues for decision-making and the extent to which FP options offered were appropriate for the patient's individual situation (Fig. 2). Some patients indicated that they missed essential information during FPC in the free-response section. This included information about gestational carriers, the influence of hormonal stimulation on a hormone-dependent tumour or the influence of hormonal stimulation and ovarian enlargement on the risk that chemotherapy would result in ovarian failure.

Decision-making and decisional conflict

At the free-response section of the questionnaire, patients revealed that their FP decision was mainly dependent on a difficult trade off between their risk of ovarian failure and their wish to start oncological therapy as soon as possible. A significant number of patients indicated that their young age, the recent start of their partner relationship, and/or the short period of time to make a decision complicated their decision-making processes. Patients had a median overall score of 25.0, with 11 patients (18%) having scores exceeding the score of 37.5 associated

Table I Baseline characteristics and determinants of experiences with counselling and decision-making.

	Participants who completed the DCS (n = 60)	
Baseline and clinical characteristics at counselling		
Age, years (mean, SD)	28.9	5.7
Diagnosis (number, percentage)		
Benign disease (nephrotic syndrome)	1	1.7%
Breast cancer	36	60.0%
Lymphoma	11	18.3%
Leukaemia	—	—
Gynaecological malignancy	5	8.3%
Bone or soft tissue tumour	4	6.7%
Tumour of the gastro-intestinal tract	3	5.0%
Central nervous system tumour	—	—
Partner relationship (number, percentage)		
No partner relationship	6	10.0%
Partner, living apart	14	23.3%
Partner, living together	40	66.7%
Parity (number, percentage)		
Nulliparous	51	85.0%
Parous	9	15.0%
Wish to conceive (1–10; mean, SD)	6.8	2.8
Level of education (number, percentage)		
Primary school or lower vocational education	3	5.0%
Secondary school or higher vocational education	17	28.3%
Higher education or university	40	66.7%
FP counsellor		
Experience		
≤ 10 consultations with female patients for FP counselling	13	21.7%
11–25 consultations with female patients for FP counselling	12	20.0%
> 25 consultations with female patients for FP counselling	35	58.3%
Counsellor actively participated in the NNF (number, percentage)		
Yes	39	65.0%
No	21	35.0%
FP options		
Patients to whom at least one FP option was offered (number, percentage)	60	100%
IVF or ICSI offered	38	63.3%
Cryopreservation of ovarian tissue offered	26	43.3%
Vitrification of oocytes offered	26	43.3%
Ovarian transposition offered	5	8.3%
FP options performed (number, percentage)		
No FP	26	43.3%
IVF or ICSI*	21	35.0%

Continued

Table I Continued

	Participants who completed the DCS (n = 60)	
Cryopreservation of ovarian tissue*	2	3.3%
Vitrification of oocytes	8	13.3%
Ovarian transposition*	4	6.7%
Follow-up		
Follow-up, years (mean, SD)	2.0	1.3
Period of counselling: July 2008–January 2011 (number, percentage)	26	43.3%
Period of counselling: January 2011–July 2013 (number, percentage)	34	56.7%
Current health status		
(Cancer) treatment successfully completed, follow-up	36	60.0%
Current treatment	22	36.7%
Diseased	2	3.3%
Current partner relationship (number, percentage)		
No	12	20.0%
Same partner as during FPC	46	76.7%
Other partner as during FPC	2	3.3%
Current wish to have a child (1–10; mean, SD)	6.5	3.0
Tried to conceive after FPC (number, percentage) (one missing)		
No	51	86.4%
Yes	8	13.6%
Conceived after FPC (number, percentage) (one missing)		
Yes (all spontaneous conceptions)	6	10.2%
No	53	89.8%
Takes care for children who did not live in the family at the moment of FPC		
No	56	93.3%
Yes, biological children from my current partner and myself	4	6.7%
Adopted children	0	0%
Children from my current partner	0	0%

NNF, Netherlands Network for Fertility Preservation; FP, fertility preservation; FPC, fertility preservation consultation.

*One patient received both IVF and ovarian transposition, while two patients received both cryopreservation of ovarian tissue and ovarian transposition.

with decision delay and feeling unsure (O'Connor, 2010). The highest conflict was indicated for the 'Uncertainty' and 'Values clarity' subscale (Table II). For the subgroup of 33 patients who had not tried to conceive and who were counselled since 2011, a comparable pattern was seen (Table II). In this group, only two patients (6%) had overall scores above 37.5.

Patients' FPC experiences in relation to decisional conflict

The influence of patient experiences and other determinants on the overall DCS score are provided in Table III. Although trends were observed for various baseline characteristics, the only items that

Table II Decisional conflict and regret scores.

	All participants (n = 60)		Participants in subgroup (n = 33)	
Decisional conflict				
Overall score (median, IQR)	25.0	(18.8; 35.0)	23.3	(17.5; 28.3)
Informed	25.0	(16.7; 33.3)	25.0	(16.7; 25.0)
Values clarity	33.3	(25.0; 47.9)	33.3	(25.0; 50.0)
Support	25.0	(8.3; 33.3)	25.0	(8.3; 25.0)
Uncertainty	29.2	(16.7; 41.7)	25.0	(16.7; 37.5)
Effective decision	25.0	(8.3; 33.3)	8.3	(0.0; 25.0)
Decision regret				
Decision regret scale (median, IQR)	8	(5; 12)	7	(5; 12)

remained statistically significantly associated with patients' decisional conflict after a Bonferroni correction concerned patient experiences with FPC. Especially negative experiences with the most basic ingredients of FPC, namely items related to the patient's ability to obtain enough information about FP options, were correlated with decisional conflict (Table III). In addition, patients who did not feel supported by their counsellor reported higher conflict. In the subgroup of participants ($n = 33$) who did not try to conceive after FPC and who had been counselled at some time since 2011, similar results as for the total study population were found for the association of patient experiences with decisional conflict (data not shown).

Decision regret

Patients had a median score on the decision regret score (DRS) of 8 (Table II). An ANCOVA assessing the influence of decisional conflict (DCS overall score) on decision regret (DRS) revealed that the decisional conflict and regret were closely related to each other ($B = 0.21$; 95% confidence interval (CI) = 0.15; 0.27; $P < 0.0001$; Spearman's ρ 0.74). The DCS overall score remained related to decision regret in our subgroup ($B = 0.18$; 95% CI = 0.10; 0.26; $P < 0.0001$; Spearman's ρ 0.57).

Discussion

This is the first study conducted in a European country with reimbursement of FP that quantitatively assessed patients' experiences with FPC in the context of decisional conflict and regret. In accordance to prior findings (Hill et al., 2012; Kim et al., 2013), the majority of patients in this study were satisfied with FPC. Although some patients wished for more information about specific subjects (e.g. the influence of hormones and ovarian enlargement on the risk that chemotherapy would cause ovarian failure), information could sometimes not be provided as our knowledge in the field is still limited.

The results of this study were consistent with earlier studies establishing a link between the extensiveness of counselling and decisional conflict or even regret. Indeed, lower regret and conflict have been observed among cancer survivors who received FPC when compared with patients

who did not benefit from this care (Letourneau et al., 2012; Mersereau et al., 2013). Furthermore, negative associations with decisional conflict have been reported for patients' fertility-related knowledge and opportunities to ask questions (Peate et al., 2011; Kim et al., 2013). It was remarkable that participants in the current study had lower decisional conflict scores (median 25.0) than patients from the USA (29.7 and 31.3) (Kim et al., 2013; Mersereau et al., 2013). Presumably, decisional conflict is higher in the American setting with not all citizens having the costs of FP reimbursed (Kim et al., 2013; Mersereau et al., 2013). Compared with 36.5 and 40.9% of the patients proceeding with an FP technique after FPC in the USA (Kim et al., 2013; Mersereau et al., 2013), 56.7% of the patients in our sample underwent FP. Despite these differences in decisions, the levels of decision regret found in the current study (median score: 8) were comparable with those previously reported for American FPC patients (mean score: 8.4). Significantly higher regret scores were obtained in an Australian population of breast cancer patients counselled more recently (mean score after conversion to a scale of 5–25: 14.8) (Peate et al., 2012).

The associations found between patients' experiences with FPC, current regret and recalled decisional conflict about the FP decision may have several explanations. First of all, there may be a causal relationship between the quality of FPC and patients' ease or difficulty in decision-making. Various studies have indicated an association between patients' limited FP knowledge and decisional conflict (Balthazar et al., 2011; Peate et al., 2011, 2012). Secondly, patients' current feelings of decision regret may have altered their reflections on their FPC and FP decision-making that took place in the past (Gilovich and Medvec, 1995). It has been shown that recalled decisional conflict can fluctuate during time, as the same patients reported various levels of recalled decisional conflict at three time-points across the first year of follow-up after FPC (Peate et al., 2012). As a third explanation for the associations found, patients' experiences, decisional conflict and regret can have (a) common cause(s).

The fact that we could not clarify whether the associations between patients' experiences, decisional conflict and decision regret were causal was one of the limitations of our study. Apart from this important limitation, we recruited female patients who were at least 16 years of age when filling in our questionnaire, limiting the generalizability of our results to paediatric populations. Our sample size was not sufficient to create a multivariable model or to study subgroups of patients with a specific diagnosis, partner relationship status, educational level or age. Nevertheless, important strengths of this study were the fact that the results were obtained via a systematic mixed methods approach in a setting where financial reasons to refrain from FP did not play a role. Moreover, our study evaluated FPC provided by various counsellors.

Several conclusions and implications for the clinical practice can be drawn from this study. As long as a causal relationship between the quality of FPC, decisional conflict and regret is not refuted, attempts should be made to optimize care in order to attain a higher quality of FP decisions. To optimize care, interventions aiming to improve patients' comprehension of the topic of FP and their feelings of being supported should be considered. Patients suggested written material before and after FPC (Hill et al., 2012; Garvelink et al., 2013a), the opportunity to meet a psychosocial counsellor (Hill et al., 2012) and the use of a decision aid (Thewes et al., 2005). Moreover, additional contact with the FP specialist following FPC (Balthazar et al., 2011) and decision aids (Peate et al., 2012; Garvelink et al., 2013b) have been shown to improve patients'

Table III Determinants of decisional conflict.

	B	95% CI	P-value*
Baseline and clinical characteristics at counselling			
Age, years	-0.01	(-0.63; 0.61)	1.0
Diagnosis (reference: tumour of the gastro-intestinal tract)			
Benign disease (nephrotic syndrome)	5.00	(-26.82; 36.82)	0.8
Breast cancer	9.61	(-6.95; 26.17)	0.3
Lymphoma	3.49	(-14.47; 21.44)	0.7
Gynaecological malignancy	7.67	(-12.46; 27.79)	0.4
Bone or soft tissue tumour	4.58	(-16.47; 25.63)	0.7
Partner relationship (reference: partner, living together)			
No partner relationship	2.81	(-8.56; 14.19)	0.6
Partner, living apart	10.55	(2.48; 18.62)	0.011
Parity (reference: parous)			
Nulliparous	-1.93	(-11.77; 7.91)	0.7
Wish to conceive (1-10)	-0.58	(-1.85; 0.68)	0.4
Level of education (reference: higher education or university)			
Primary school or lower vocational education	12.55	(-3.56; 28.66)	0.12
Secondary school or higher vocational education	-0.33	(-8.12; 7.46)	0.9
FPC experiences			
Enough time available for counselling	-10.59	(-15.28; -5.89)	<0.0001
Had the opportunity to ask all questions	-12.86	(-17.14; -8.57)	<0.0001
Counsellor was aware of personal importance of specific issues for FP decision	-2.82	(-6.82; 1.19)	0.17
Involved in decision-making in a pleasant way	-4.88	(-8.77; -0.98)	0.015
Supported by counsellor during decision-making	-6.51	(-9.89; -3.13)	0.0003
All applicable FP options were discussed	-7.49	(-11.14; -3.83)	0.0001
Benefits and disadvantages of options were clearly explained	-8.28	(-12.79; 3.77)	0.0005
Counsellor provided information not yet provided by the oncologist/physician	-3.30	(-7.02; 0.42)	0.081
Written or online information was provided	-3.93	(-6.97; -0.89)	0.012
FP options offered were appropriate	-2.04	(-4.48; 0.40)	0.099
FP counsellor			
Experience (reference: >25 consultations)			
≤10 consultations	0.16	(-8.77; 9.09)	1.0
11-25 consultations	-0.04	(-9.24; 9.16)	1.0
Counsellor actively participated in the NNF (reference: yes)			
No	-0.78	(-8.15; 6.60)	0.8
FP options			
IVF or ICSI offered (reference: no)	-5.02	(-13.38; 3.35)	0.2
Cryopreservation of ovarian tissue offered (reference: no)	0.39	(-7.86; 8.63)	0.4
Vitrification of oocytes offered (reference: no)	2.01	(-6.30; 10.33)	0.6
Ovarian transposition offered (reference: no)	-5.32	(-19.03; 8.39)	0.4
FP performed (reference: no)	-7.59	(0.78; 14.40)	0.030
Follow-up			
Follow-up, years	3.19	(0.69; 5.70)	0.013
Current health status (reference: diseased)			
(Cancer) treatment successfully completed, follow-up	2.56	(-4.77; 9.90)	0.5
Current treatment	12.01	(-8.02; 32.03)	0.2
Current partner relationship (reference: other partner as during FPC)			
No	-8.61	(-29.27; 12.04)	0.4
Same partner as during FPC	-11.98	(-31.5; 7.56)	0.2

Continued

Table III Continued

	B	95% CI	P-value*
Current wish to have a child (I – 10)	–0.11	(–1.32; 1.10)	0.9
Tried to conceive after FPC (reference: no)			
Yes	–7.84	(–17.98; 2.31)	0.13
Conceived after FPC (reference: no)			
Yes	–7.39	(–18.95; 4.18)	0.2

After a Bonferroni correction ($P \leq 0.05/38$ statistical tests), variables for which a P -value of $P \leq 0.0013$ was found were considered statistically significantly related to decisional conflict. Unstandardized coefficients (B) with 95% confidence intervals (CIs) in parentheses are demonstrated here. Items with a statistically significant association with the Decisional Conflict Scale (DCS) score are provided in bold. Example 1: For each year that patients were older, the patients' mean overall DCS score was 0.01 points lower. Example 2: The mean DCS score of nulliparous women was 1.93 points lower than that of parous women (reference).

NNF, Netherlands Network for Fertility Preservation.

* P -value and CIs resulting from ANCOVA with the overall score on the DCS as a dependent outcome variable.

knowledge. Experiences with FPC and FP decision-making should be further investigated in prospective studies to obtain information about the causality of the association between the quality of FPC, decisional conflict and regret. With sufficiently large samples, researchers could investigate whether there are subgroups of patients at risk for developing regret who may be helped with personalized interventions.

Acknowledgements

The authors gratefully acknowledge Simone A.E. Postma, MD, for her contribution to the interview coding and Willemijn J Geense, MD, for her contribution to the data-collection.

Authors' roles

This study was designed by C.C.M.B., W.L.D.M.N., M.A.F.T., D.D.M.B. and L.B. C.C.M.B. collected information on the patients counselled at the Rmuc during our study period. L.B. and Ö.B. collected the medical information presented in this paper. L.B. performed the qualitative interviewing, and coded the interviews independently from Simone A.E. Postma (acknowledgements). W.L.D.M.N. crosschecked the interviews and, together with L.B. designed the framework. The questionnaire was designed by L.B. and W.L.D.M.N. with help from C.C.M.B., D.D.M.B. and C.M.V. Ö.B. distributed the questionnaire and collected all of the results with help from L.B. Data were analysed by L.B. and J.I. and interpreted by all authors. L.B. wrote a draft of this manuscript. All authors critically revised one or more versions of the paper and approved the final version.

Funding

This work was supported by the Radboud Institute for Health Sciences, and an unconditional grant from Merck Serono.

Conflict of interest

None declared.

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